

## Data Collection Tool for the Endocrinologist

Directions: Pull the last 15 or more charts of patients who were referred for abnormal growth or pubertal development and who you have been following for at least 12 months in your practice.

Answer the questions based on actual documentation and not on memory or inference.

1. Were all essential growth parameters discussed with the patient/family at the most recent endocrinologist visit?  
 Yes       No
2. Was growth velocity documented at the most recent endocrinologist visit?  
 Yes       No
3. Was upper to lower segment ratio documented at the initial endocrinologist visit?  
 Yes       No
4. Were the results of a pubertal assessment discussed with the patient/family at the initial endocrinologist visit?  
 Yes       No       N/A, patient not of pubertal age, no clinical indications, or no concerns identified
5. Was mid-parental height calculated and documented by your practice?  
 Yes       No       Not obtainable (ie, one parent not involved, child adopted without biological parent information, etc)
6. If the patient is on growth hormone therapy, was a bone-age documented within the past 12 months?  
 Yes       No       N/A, patient not on growth hormone therapy

*If Yes to question 6:*

6a. Was the bone age older than 14 or 16 years for a female or male, respectively?  
 Yes       No

*If Yes to question 6a*

6b. Was growth hormone therapy discontinued?  
 Yes       No

7. Did your practice attempt to obtain all of the following items from the referring provider?  
 History  
 Physical examination  
 Growth charts  
 Medications, if any  
 Laboratory and imaging results, if any  
 Summary of case (ie, impression of growth concern)  
 Contact information of the referring provider  
 Contact information for the patient/family  
 Yes       No
8. Were all test results documented in the patient's written care plan by your practice?  
 Yes       No       N/A, tests still in progress, or none ordered
9. Were educational materials or web-based links provided by your practice to the patient/family about the suspected growth or pubertal development concern?  
 Yes       No
10. Was an assessment of potential growth-related psychosocial issues for the patient and family made?  
 Yes       No

# Growth: Addressing Concerns and Management

11. At the most recent endocrinologist visit, check all that apply regarding the [written care plan](#) for growth or pubertal disorders:

- a)  The plan was established, updated, or maintained
- b)  The plan was provided to the patient/family
- c)  The plan was shared with the referring physician, following the visit
- d)  No care plan documented in the medical record

12. Were potential side effects and benefits of treatment communicated to the patient/family?

- Yes
- No
- No treatment recommended

## Appendix

### Essential Growth Parameters

#### Generalist requirements at every health supervision visit

##### **For children ages 0 through 23 months, plot on WHO charts:**

- Head circumference
- Weight-for-age percentile
- Length-for-age percentile
- Weight-for-length percentile (recommended, but not required for this exercise)

##### **For children age 2 years and older, plot on CDC charts:**

- Weight-for-age
- Stature-for-age
- BMI-for-age

##### **For all ages**

- Pubertal staging

#### Generalist requirement when abnormal growth is suspected

- Mid-parental height

#### Endocrinologist requirements at every health supervision visit

- All generalist requirements listed above
- Growth velocity

#### Additional endocrinologist requirements at the initial visit

- Upper to lower segment ratio
- Mid-parental height

## Mid-parental Height (MPH) Calculations

Mid parental height can be calculated in the following two ways:

#### MPH calculation (inches):

For girls: ((Father's height - 5 inches) + Mother's height) divided by 2

For boys: ((Mother's height + 5 inches) + Father's height) divided by 2

1 standard deviation (SD) = 2 inches

2 SD = 4 inches

Target height range = mid-parental height +/- 4 inches.

1 inch = 2.54 cm

#### MPH calculation (centimeters):

For girls: ((Father's height - 13 cm) + Mother's height) divided by 2

For boys: ((Mother's height + 13 cm) + Father's height) divided by 2

1 standard deviation (SD) = 5.1 cm (many clinicians round to 5)

2 SD = 10.2 cm (rounded to 10 cm)

Target height range = mid-parental height +/- 10.2 cm

95% of normal children have a predicted adult height that is within 4 inches above or below the mid-parental height calculation.

## Psychosocial Issues (Growth and Pubertal Development-related)

Among others, identify and address the following psychosocial issues based on the patient's age, patient/family requests, and clinical indications founded on your team's assessment:

1. Coping with growth and pubertal development disorders, including peer relations and social adjustment
2. Family involvement
3. Non-adherence
4. Anxiety and depression
5. Disordered eating behaviors
6. Risk-taking behaviors such as drug abuse, alcohol, and tobacco use
7. Contraception
8. Preparing for college
9. Communication with parents and with growth care team
10. Transition to adult health care

**Note:** This list is not intended to be an exhaustive inventory of psychosocial issues requiring surveillance, but rather some essential and practical issues common in growth and pubertal care.

## Upper to Lower Segment Ratio

The **Upper to Lower Segment Ratio** is defined as the length from the top of the symphysis pubis to the top of the head, divided by the length from the top of the symphysis pubis to the sole of the foot. The segments are most easily calculated by measuring from the symphysis pubis to the floor to measure the lower segment. Next, the lower segment is subtracted from the total height or total length to give the upper segment. Finally, the length of the upper segment is divided by the length of the lower segment.

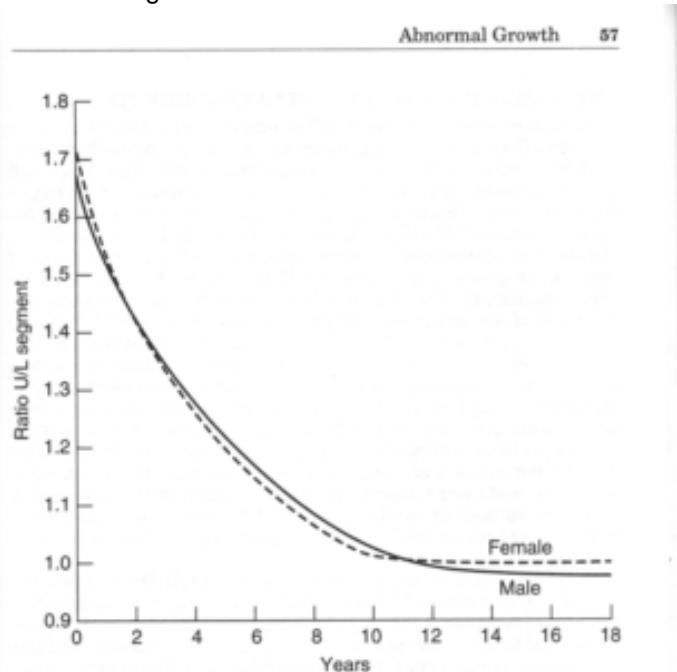


Fig. 5-7. Upper- to lower-segment ratio. (From Engelback LW. The diagnosis and treatment of endocrine disorders in childhood and adolescence. Springfield, IL: Charles C Thomas Publishers, 1965, with permission.)

is expressed in standard deviations from the average reading for chronologic age. Standard deviations vary with age; one standard deviation may be only 2 months during the first year to 1 year at 15 years. Increased accuracy in the technique is accomplished by radiologists with the most practice; unfortunately, most general radiologists who are not associated with a pediatric center do not read many bone ages, and their readings may not be quite correct. With a bone age over 6 years and an accurate determination of stature, final height can be predicted by the Bailey-Pinneau tables found at the end of the Greulich and Pyle atlas. The Roche Wainer Thissen (RWT) method allows prediction of eventual adult height in younger children. Other methods of height prediction are in use in Europe, and computerized methods of bone-age evaluation in development may increase accuracy in the future.

From Styne, MD, *Pediatric Endocrinology, Upper-to-Lower Segment Ratio*, Lippincott, Williams and Wilkins, copyright 2004, pg 57, fig 5-7.

Adapted from from Engelback, LW. *The diagnosis and treatment of endocrine disorders in childhood and adolescence*. Springfield, IL: Charles C Thomas Publishers, 1965.

## Written Care Plan

An effective care plan for growth concerns should meet all of the patient/family's medical, psychosocial, and educational needs. It should have the following characteristics: It should be comprehensive, guideline-based, developed in partnership with the family (and, when appropriate, the patient), understandable by the patient and family, provided in a coordinated and comprehensive manner to the patient's medical home and referral provider(s), and inclusive of a medical summary with condition-specific action plans

Common elements of a comprehensive guideline-based care plan for growth-related care:

- ✓ Growth diagnosis(es)
- ✓ Treatment plan
- ✓ Coexisting diagnoses
- ✓ Medications, supplements, vitamins, dosages
- ✓ Other therapies
- ✓ Allergies
- ✓ Recent clinical exam results
- ✓ Recent diagnostic test results
- ✓ Extracurricular activity involvement
- ✓ Hospitalizations
- ✓ Educational status
- ✓ Sleep habits
- ✓ Psychosocial issues
- ✓ Patient or family concerns
- ✓ Recommended physical activity, with any needed adaptations
- ✓ Recommended dietary adaptations or changes
- ✓ Patient or family limitations to following the plan
- ✓ Educational materials that were provided to patient/family
- ✓ Team members, and their roles, responsibilities, and contact information;
- ✓ A medical summary with condition-specific action plans
- ✓ Transition plan to adult care (as appropriate).